

RDG End of Year Report 2012

Name of RDG	ARPKD Rare Disease Working Group
Name of Coordinator	Dr Larissa Kerecuk
Name of Administrator	Melanie Dillon
Name of person/person's cleared to work with patient identification	Melanie Dillon
RDG meetings: Summary <i>(append written minutes if that is easier)</i>	Minutes of Working group meetings from June and December 2012 attached.
Patient Information meetings :Summary <i>(append written minutes if that is easier)</i>	Patient Information Day programme attached. Key presentations also available online via the PKD Charity's website and RareRenal.org.
Grant applications submitted	
Grants awarded	
Publications and presentations	Patient Information Day presentations detailed in attached minutes. RaDAR update presentation given at BAPN meeting in November, showing data entry process.

Highlights (free text)	<p>First UK ARPKD Patient Information Day held 30th June 2012. Attended by over 80 delegates from across the UK.</p> <p>2013 event planned for 6th July.</p> <p>International collaborations established with Prof Lisa Guay-Woodford (US) and Dr Max Liebau (Europe).</p> <p>10 out of the 15 eligible ARPKD patients at BCH will have been consented into Radar by the end of March 2013.</p>
Problems (free text)	<p>Limited data can be uploaded at present into RaDAR as full data fields are not yet available.</p>